A Guide Through the Maze of Long-term Care

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Complicated requirements regarding eligibility and coverage as well as variations in the availability of programs confuse even the most diligent physicians trying to advise elderly patients about health care services. Nevertheless, awareness of such government and community resources is critical because physicians play an essential role in assisting the elderly to receive maximum health care benefits, particularly during long-term illness.

PHYSICIANS WHO CARE for elderly patients frequently need to call on a variety of community resources. Alas, the complicated eligibility requirements, the regulations about how much of what is covered, and the varying availability of services place even motivated physicians in a labyrinth, often without so much as a guidebook, let alone a guide. A major factor that limits effective use of resources is the need to determine a patient's eligibility for the services he or she requires. To the extent that these programs are increasingly supported by public funds, physicians face a confusing plethora of alpha/numeric acronyms. The purpose of this paper is to provide a guide through the maze of federal programs designed to serve the elderly. Along the way, we hope to point out areas of overlap and of underservice. Finally, we will review available data to offer clues about how to identify those most likely to be admitted to institutions.

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Major Federal Programs

There are essentially four major federal programs that provide important health-related benefits for old people. Each operates under a different mandate and each is targeted to a different (but potentially overlapping) constituency. Each provides a different package of services. All but one of the programs (Medicare) are run in collaboration with one or another unit of government. Thus, the consistency of program operations varies from state to state and, in some cases, from county to county.

Table 1 summarizes the major federal programs for elderly persons. The most familiar, Medicare, more formally known as Title XVIII of the Social Security Act, is organized as an insurance entitlement program for acute medical care. It comprises two related parts. Part A covers primarily hospital care and a small amount of posthospital care. Part B deals with supplemental medical insurance and includes a variety of services that augment the medical care of the elderly. Virtually all people in this country 65 years or older are enrolled in Medicare. For Part A there is no additional cost and for Part B there is a small monthly premium.

Medicare is essentially a program that covers

acute illness, with a major focus on hospital care. It is organized similarly to most health insurance programs. It provides hospital coverage under a "reasonable cost" reimbursement formula and a limited amount of nursing home care in skilled facilities. The latter is intended to be a continuation of hospital care but at a lower (that is, cheaper) level. Patients must have had a minimum of three days in hospital to be eligible for skilled nursing coverage under Medicare. They are expected to have a condition that can respond to long-term care. The program operates, as most

TABLE 1.—*Summary of Major Federal Programs for the Elderly*

Program	*Eligible Population*	*Services Covered*	*Deductibles and Copayments*
Medicare (Title XVIII of the Social Security Act)			
Part A: Hospital insurance	All persons eligible for Social Security and others with chronic disabilities such as end-stage renal disease plus voluntary enrollees 65+.	Per benefit period, "reasonable cost" for 90 days of hospital care plus 60 lifetime reservation days; 100 days of skilled nursing facility (SNF); home health visits (see text).	$204* deductible and copayments of $51/day for hosp. days 61-90; $102/day for lifetime reserve days; $22.50 for SNF days 21-100.
Part B: Supplemental medical insurance	All those covered under Part A who elect coverage. Participants pay a monthly premium of about $10.	80% of "reasonable cost" for: Physicians' services; supplies and services related to physician services; outpatient, physical and speech therapy; diagnostic tests and x-rays; surgical dressings; prosthetics; ambulance; home health visits.	$60* deductible and 20% copayment.
Medicaid (Title XIX of the Social Security Act)	Persons receiving Supplemental Security Income (SSI) (such as welfare) *or* receiving SSI and state supplement *or* meet lower eligibility standards used for medical assistance criteria in 1972 *or* eligible for SSI *or* were in institutions and eligible for Medicaid in 1973. Medically needy who do not qualify for SSI but have high medical expenses are eligible for Medicaid in some states; eligibility criteria vary from state to state.	*Mandatory services* for categorically needy: Inpatient hospital services; outpatient services; SNF; limited home health care; laboratory tests and x-rays; family planning; early and periodic screening, diagnosis, and treatment for children through age 20. *Optional services* vary from state to state: Dental care; therapies; drugs; intermediate care facilities; extended home health care; private duty nurse; eye glasses; prostheses; personal care services; medical transportation and home health care services. (States can limit the amount and duration of services.)	None, once patient spends down to eligibility level.
Title XX of the Society Security Act	All recipients of Aid to Families with Dependent Children (AFDC) and SSI. Optionally, those earning up to 115% of state median income and residents of specific geographic areas.	Day care; substitute care; protective services; family counseling; home-based services; employment, education and training; health-related services; information and referral; transportation; day services; family planning; legal services; home-delivered and congregate meals.	Fees are charged to those with incomes greater than 80% of state's median income.
Title III of the Older Americans Act	All persons 60 years and older. Low income minority and isolated older persons are special targets.	Homemaker; home-delivered meals; home health aides; transportation; legal services; counseling; information and referral plus 19 others. (Fifty percent of funds must go to those listed.)	Some payment may be requested.

*Medicare deductibles are scheduled to increase. Hospital deductible under Part A is projected to be $256 by January 1982. Medical deductible under Part B has been increased to $75.

insurance programs, with a combination of deductibles and copayments. The deductibles are determined on the basis of the average cost of a hospital day and the copayments to approximately a quarter of a hospital day's cost. A similar system with copayment is used for nursing home days. In both cases, the copayments begin sometime after the patient has been admitted to the institution. The patient is eligible for coverage on a per-benefit-period basis. There are also limitations of coverage with regard to expenditures per episode of illness. Part B operates with similar deductibles and copayments, but it also has the complication of paying less than reasonable cost (defined on the basis of group norms and previous billing history). It is important to appreciate that Medicare is the major source of hospital payment for older people. Although it does not cover any substantial proportion of nursing home costs, it is the mechanism under which many other services (including physicians' services) to nursing home patients are reimbursed.

Medicaid is a welfare program authorized under Title XIX of the Social Security Act. This program is jointly operated by federal and state governments. The federal government provides between 50 percent and 78 percent of the state's cost of underwriting health services to the poor. Federal guidelines set minimum standards, which the state can then, at its option, build on to increase benefits or eligibility. The principal targets of the program are those persons covered under categorical welfare programs (such as families with dependent children, the aged, blind, permanently disabled and medically needy). The categorically needy components of the aged, blind and disabled were combined under a federally sponsored program, Supplemental Security Income (SSI), in 1974. The elderly are thus identified as being either SSI recipients or medically needy. Medicaid is a program designed to serve people who lack their own financial resources. Thus, there are no deductibles or copayments. However, many critics of the program have pointed out that it imposes a burden of poverty as a condition of eligibility. A person is required to divest himself of his own resources (the so-called spend-down requirement) before becoming eligible for Medicaid assistance. The program consists of two groups of services: mandatory services and a larger set of optional services. The latter can be provided at the discretion of the state, which can set limits on the amount and duration of such care. In fact, even the mandatory services can be expanded or contracted at the option of a state government. The states also have the ability to set payment levels, which cannot exceed what is paid for private care.

In contrast to the two programs just described, the next two are primarily social service programs with some medical components. Under Title XX of the Social Security Act (known as the Social Service Amendments), federal funds are paid to state government agencies as block grants based on state populations. The states are paid 75 percent of social service program costs up to their respective Title XX ceilings (90 percent for family planning costs). The eligible population includes those people covered under categorical welfare programs and, at the state's option, other groups identified on the basis of income or special needs. A wide variety of services are available under the program. General mandates of the program can be summarized under five broad goals: (1) to help people become or remain economically self-supporting; (2) to help people become or remain self-sufficient; (3) to protect children and adults who cannot protect themselves from abuse, neglect and exploitation and to help families stay together; (4) to prevent and reduce inappropriate institutional care as much as possible by making home and community services available, and (5) to arrange for appropriate placement and services in an institution when this is in a person's best interest.

Title III of the Older Americans' Act mandates a series of services targeted at older people (here defined as those who are 60 years or older). This program is supported by federal grants to state and then to local agencies to plan and coordinate services to older persons comprehensively. There are no income criteria, although some payment can be requested for those with income exceeding a threshold set by the local agency.

Home Care

As can be seen from even the brief summary in Table 1, several forms of care appear to be common across the various programs, although the eligible populations may vary. Perhaps the most universally available in theory is home care. Certainly, all of the programs provide at least some home-care services. Because of the growing interest in the use of home care as a way of keeping people in the community, it may be worthwhile

to spend a little time looking at the several programs.

Table 2 points out some of the differences in home care coverage provided under Medicare, Medicaid and Title XX. Medicare has recently broadened its coverage of home health services by rescinding the requirement that the patient previously be admitted to hospital for at least three days and by placing no limit on the number of visits covered under the program. However, persons eligible for coverage under Medicare must still meet certain criteria. They must be homebound and be certified by a physician as requiring "intermittent" skilled care; recertification is required every 60 days. Services can be provided only by a certified home health care agency. The patient must be certified as requiring one of several "primary services" (such as skilled nursing, physical therapy or speech therapy) to receive the secondary services (such as social work, home health aide services and occupational therapy). (Occupational therapy was promoted to a primary service as of July 1981, but in October 1981 it reverted to a secondary service with the option to continue it after the primary services are discontinued.) Except for light housekeeping around the patient's bed, homemaking is precluded.

Medicaid is more flexible in its eligibility requirements and in the services included. Although the need must be certified by a physician, the patient need not require skilled care (some patients may need lesser care). The state has the option of using the same homebound criterion as with Medicare. As noted earlier, a limited amount of home health care is mandatory under the federal guidelines, but states can opt for expanded home-care coverage, including personal home care. The latter represents health-related support services prescribed by a physician and given under the supervision of a nurse; these can encompass a wide variety of homemaking and other services.

The eligibility criteria for Title XX vary from state to state, as do the variety of services that can be provided under this program. Because Title XX has tripartite sponsorship, the variation can occur even within states at local options. One of the interesting aspects of the Title XX home-care program is the provision for three types of payment. Local agencies can opt to provide services directly themselves; they can contract with private agencies, or the recipient can enter into an agreement with an independent provider who does not work for any agency. The last provision has prompted much controversy in home-care circles about the problems of maintaining quality in the absence of any form of supervisory systems or institutional responsibility.

As can be seen in Table 2, home care represents a very small proportion of the total dollars in either the Medicare or Medicaid program. Medicare spent about 2 percent of its total program dollars on home health care; with Medicaid the

TABLE 2.—*Home Care Provided Under Various Federal Programs*

	Medicare	*Medicaid*	*Title XX*
Eligibility criteria ...	Homebound; need skilled care; need certification by physician.	State can use homebound criterion; not limited to skilled care; need certification by physician.	Vary from state to state.
Payment to provider .	Reasonable costs.	Varies with state.	Three modes of payment possible: (1) direct provision by government agency; (2) contracting with private agency; (3) independent provider.
Services covered	Home health, skilled nursing, physical or speech therapy as primary services. Secondary services (social work and home health aide) available *only* if primary is provided. Position of occupational therapy in service hierarchy ambiguous.*	Limited home health mandatory; expanded home care optional; personal care in home optional.	Wide variety of home services allowed including: home health aide, homemaker, chore, meal services.
Percent of program dollars spent on home care	2%	0.1% to 0.5%	10% to 15%

*Occupational therapy was authorized as a primary service beginning in July 1981, but, as of October 1981, it has become an "extended" secondary service, which may continue if needed after primary services are discontinued.

TABLE 3.—*In-Home Care Expenditures and Beneficiaries (Fiscal Year 1977)**

Program	*Expenditures ($ millions)*	*Beneficiaries (in thousands)*
Medicare	458	690
Medicaid	179†	300
Title XX	491‡	489

*From US DHHS, HCFA: Home Health and Other In-Home Services: Titles XVIII, XIX, and XX of the Social Security Act: A Report to Congress. Washington, DC, Government Printing Office, no date (mimeo).

†State and federal.

‡Federal, state, local and private.

proportion varied from state to state but was generally less than 1 percent. New York state has the highest proportion of program dollars spent for home care: 4.4 percent. Title XX shows similar variability at a higher level (almost ten times that for Medicaid). In fiscal year 1978 California had the highest proportion of expenditure of Title XX funds for home services: 30 percent.[1]

Looked at another way, the magnitude of the various federal programs for home care suggests that Title XX and Medicare play a larger role than Medicaid (see Table 3). If one uses total expenditures, the largest pool of funds comes from Title XX. The largest number of beneficiaries served is covered under Medicare, but the numerous restrictions have the effect that Medicare's home health services are largely for persons who are acutely ill. It is indeed possible that some beneficiaries receive coverage under more than one program.

To illustrate the variation in Medicaid coverage of home health services, Table 4 summarizes elements of the programs as implemented in a selection of western states. Arizona i. conspicuously absent because it does not have a Medicaid program.

Nursing Homes

The largest expenditure for long-term care, however, involves nursing homes. Often as a result of the perverse public payment system,[2] nursing homes continue to dominate the scene. Almost 40 percent of total Medicaid expenditures and about 75 percent of Medicaid expenditures for the elderly go for nursing home care. Thus, this type of care has emerged as essentially a welfare program.

As shown in Figure 1, the funding of nursing home care is very different from that for health care in general. The predominant role played by

TABLE 4.—*Characteristics of Medicaid Home-Health Programs**

State	*Home-bound*	*Skilled Care*	*Prior Authorization*	*Limit No. of Visits*	*Optimal Services†*				*Eligibility‡*			*Provider Supply*		*Reimbursement§*		
					PT	*OT*	*SP*	*AUD*	*CN*	*MH*	*BI*	*Total*	*Proprietary Number*	*Method*	*Cost/Nursing Visit*	*Certificate of Need*
California	X	X	>1 evaluation visit/6 weeks	..	..	..	..	..	X	X	X	111	36	Max	$26.10	..
		Postinstitutional care														
Colorado	..	..	....	150	..	..	..	..	X	..	X	32	0	LCOC	$28.00	..
Hawaii	..	..	SP, AUD	..	X	X	X	X	X	X	X	6	1	Medicare upper limit	$25.25	Yes
Idaho	..	..	....	..	X	X	X	X	X	..	..	11	2	UCR	$15.00-$30.00	..
Montana	..	..	PT, OT, SP	200/yr	X	X	X	..	X	X	Part B	15	0	Cont	$11.46-$28.00	Yes
Nevada	..	..	....	..	X	X	X	X	X	..	Part B	6	2	C-B	$27.13	..
Utah	X	..	Supplies>$100	..	X	X	X	X	X	X	Part B	9	0	Cont	$14.00	..
Washington	..	..	>$350 cost/mo	..	X	X	X	..	X	X	Part B	26	0	Max	$32.90	..
Wyoming	X	..	....	..	..	..	..	..	X	..	..	14	0	LCOC	$30.10	..
		Supplies limited to those available through a home-health agency														

*From US DHHS, HCFA: Home Health and Other In-Home Services: Titles XVIII, XIX, and XX of the Social Security Act: A Report to Congress. Washington, DC, Government Printing Office, no date (mimeo).

†Optimal services: PT = physical therapy; OT = occupational therapy; SP = speech therapy; AUD = audiology.

‡Eligibility: CN = categorically needy: Persons who generally meet income resource or other standards for Supplemental Security Income (SSI) or state supplementary payments under SSI or Aid to Families With Dependent Children. MN = medically needy: Persons who would be categorically needy except for their slightly higher income and/or resources, but who, in the view of the state, cannot afford to pay their medical bills. BI = buy-in: Persons who are members of a state's Medicaid coverage group who are also eligible to enroll in Medicare Part B.

§Reimbursement: Max = maximum allowance: Maximum amount established by the state for given product or service; state pays lower of actual charge or maximum allowance. Cont = contract: State purchases goods or services through a contract mechanism and pays the amounts specified. UCR = usual, customary and reasonable: An amount based on a provider's costs, such as annual operating costs. C-B = cost-based: State pays for services based on periodic allowable provider costs, such as annual operating costs. LCOC = lower of costs or charges.

Medicare in the funding of acute care is not seen in nursing home coverage, where Medicare is responsible for only about 2 percent of the total bill. Most public funds come from Medicaid. In 1976 almost 60 percent of all days spent in nursing homes were financed either totally or in part by that program.[2] But the figure does not show the dynamics of the situation. Almost a third of the patients who eventually become Medicaid patients enter as private-pay patients. Studies have shown that as many as two thirds of the group entering nursing homes as private-pay patients convert to Medicaid status some time during their stay. Of those who entered on Medicaid status, a third went on Medicaid at the time of admission.[2] This growing dependence on Medicaid is a particular problem because such status reduces the patient's chance of ever returning to the community. To get on Medicaid, the patient has had to spend away or sign away most of his assets. He thus has fewer resources on which to draw, were he to leave the nursing home.

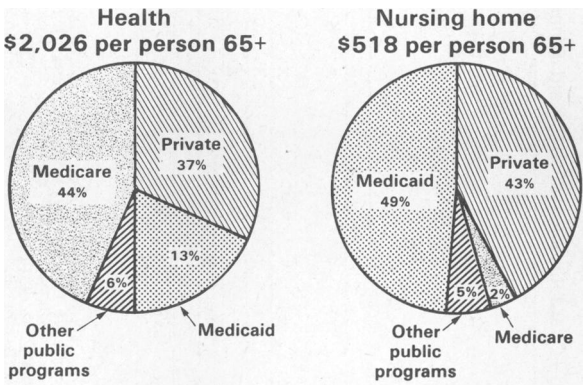

Figure 1.—Sources of health and nursing home expenditures.

TABLE 5.—*Comparison of Payment Sources for Nursing Home Residents and Discharges**

Primary Source of Payment	1977 Residents		1976 Discharges	
	Percent Covered	Average Monthly Charge ($)	Percent Covered	Average Monthly Charge ($)
Own income or family support	38.4	690	37.5	747
Medicare	2.0	1,167	17.0	1,300
Medicaid				
Skilled	20.0	873	18.0	767
Intermediate	27.0	610	17.1	597
Other government assistance or welfare	6.4	508	3.8	524
All other sources†	5.3	440	6.6	462

*From US DHHS, PHS, NCHS: The National Nursing Home Survey: 1977 Summary for the United States (PHS 79-1794). Vital and Health Statistics Series 13, No. 43. Hyattsville, MD, NCHS, 1979.
†Includes Veterans Administration.

Payment sources for nursing home care are illustrated in Table 5. The data, drawn from the 1977 National Nursing Home Survey, contrast the payment for residents with that for patients discharged. Several differences underline the dynamic nature of the nursing home population. In contrast to commonly held stereotypes about nursing home patients, the turnover for many patients is relatively rapid.[3] Again, data from the 1977 National Nursing Home Survey indicate that a third of nursing home patients are discharged within a month and more than half within three months. (In both cases, almost 80 percent are discharged alive.) Therefore, it is often critical to distinguish between reference to nursing home patients in terms of a cross section of residents or a cohort of admitted or discharged patients. The latter are made up of about equal numbers of long-stay and short-stay patients, while the former are predominantly long-stay. Some of these differences are apparent in Table 5 and account for the much greater role of Medicare in the coverage of discharged patients than residents and the correspondingly smaller proportion of that care provided by Medicaid and other government assistance programs. Similarly, one might conclude that the discharges were more likely to represent patients with somewhat more intensive care because their costs (other than those covered by Medicaid) tended to be higher than those for residents almost a year later.

We understand less about the factors that predict a patient's likelihood of entering a nursing home. We have progressed beyond what is now called the "5 percent fallacy," the simplistic statistics that report that approximately 5 percent of the population older than 65 are in a nursing home at any one time. As a first step, we can appreciate the heterogeneity of this distribution, made up of only 1 percent of those aged 65, 6 percent of those about 75 years old and more than 20 percent of those 85 years or older. From a longitudinal perspective, merely by looking at deaths we can show that 20 percent to 25 percent of persons aged 65 or older die in a nursing home.[4,5] By longitudinally following aged cohorts, investigators suggest that the proportion of elderly people who spend some time in a nursing home may be as much as 40 percent.[6,7]

But it is less clear how to identify those most likely to be admitted to nursing homes. Such an issue is critically important when we discuss the use of community services to replace or delay the

use of nursing homes. At the most basic level, we note that, compared with persons living in the community who are 65 years of age or older, nursing home residents are overrepresented by unmarried, white females. A government report comparing the disability of nursing home and community residents has been used as the basis for the often-cited statistics that for every person living in a nursing home, there are three equally disabled persons living in the community.[8] Such an observation, if correct, would strongly endorse the critical role of social supports (primarily informal, unpaid support systems like family and friends).[9,10] However, there have been substantive criticisms of both the methodology employed in the comparison[11] and the measures used to assess disability.[12] Nonetheless, social support has recurred in several studies as an important predictor of a person's likelihood of avoiding admittance to a nursing home.[13,14]

Trying to identify factors that predict an elderly person's likelihood of entering a nursing home is not encouraging. Few consistent patterns emerge. Weissert[15] could explain little of the variance in nursing home days using a combination of demographic (such as age, sex, race and marital status) and functional variables (such as mental functioning, physical functioning and diagnosis). In contrast, McCoy and Edwards,[14] looking at aged welfare recipients, found the probability of institutionalization associated positively with functional impairment, advanced age, household isolation, presence of nonrelatives and white racial background. Admittance to an institution was less likely in the presence of frequent contacts with friends and relatives and the propinquity of children.[14]

Coordinating and Managing Services

The complexity of the programs under Titles XVIII, XIX and XX of the Social Security Act, the unpredictable array of services that may be available through the Area Agencies on Aging, and the host of other public, voluntary or proprietary services that could be arranged for a patient needing long-term care defy ready description. Let us consider for a moment the patient's need rather than the characteristics of the largest programs. An older patient with multiple functional impairments may need, in addition to prompt diagnostic and therapeutic health services, lodgings suitable to his condition, meals, cleaning services, laundry assistance, personal nursing, transportation, confidence that help will be available in an emergency, companionship, mental stimulation and, perhaps, economic assistance to purchase other items.

Two points are important when one compares a patient's needs with the array of services available in a particular community. First, the ability to pay by no means insures that patients and their families will be able to identify and piece together a package that maintains their independence. Second, even though the legislated programs we have reviewed include a range of home services, the availability of such services is far from universal. Although one-stop shopping is rarely available, in most urban areas services can be mixed and matched until the patient is quite well outfitted. In many rural and surburban areas, the inventory of services is more threadbare and, to continue the metaphor, the outfit may need to be creatively and patiently stitched together for each client.

The physician alone need not shoulder the burden of arranging for social and health-related services for his office patients or care for his hospital patients after discharge. Indeed, the physician sensitive to the needs of geriatric patients and the peculiarities of the resources will draw on other expertise often and early. For patients in hospital, social workers need to begin the discharge-planning process early; service packages take time to arrange, often including discussions with family members regarding who may need to supply some of these services. From the physician, the social workers need to know the actual and anticipated functional limitations of the patient and the nature of the ongoing medical regimen. It is equally critical that private-pay patients as well as those near poverty level receive referrals to hospital social services when long-term care is necessary. Too often those patients who might be best able to use some of their own funds to sustain a preferred residency in the community believe that they have no alternative to institutional placement. Many posthospital patients (such as those with fractured hips or strokes) reach a point where they have received maximum benefit from acute care and are eligible for Medicare's 100 days of skilled nursing home care. At that point, counseling and joint planning with the patient can lead to a home care solution or to a planned short-term use of a nursing home; the latter requires that the patient and his or her family not foreclose

options to return to the community by closing up apartments and taking other irrevocable steps.

The physician may observe gradual deterioration in the functioning of a patient living in the community and often the patient's relatives are at their wits' end. Here, too, it is possible to make a referral to a community resource. A Visiting Nurse Association, the local health department or a Multipurpose Senior Center is a good place to start. Physicians should also be aware of the demonstration projects currently under way in many communities that provide a case management function. Such demonstrations take advantage of waivers of Medicare or Medicaid rules to bypass eligibility rules or provide an expanded array of services not usually covered. Essentially, the case manager assesses a client's needs and attempts to introduce a flexible service plan, sometimes cutting across usual program lines. In California, for example, the Multipurpose Senior Services Program offers case management to limited numbers of clients in eight different communities. It is critical that physicians, who tend to be the first line of defense against long-term care problems, be aligned with such community-based case management efforts.

The Physician's Role

Because so much of long-term care is cast in a medical mold forged by federal programs, the physician's role is pivotal. A physician's order, or at least concurrence, is a prerequisite to Medicare and Medicaid funding of many nonphysician services. A patient cannot receive nursing home or home care funding by these programs without a physician's request for these services. The physician is sometimes placed in a difficult position; he recognizes the patient's need for service, but the eligibility criteria may not fit the situation. He is tempted then to misrepresent the patient to make the patient's circumstances conform to an imperfect system. The need to find sufficient medical justification to put in place services to meet evident social needs has led to a great deal of frustration.[16]

The physician's critical role imposes another responsibility. Labels applied too readily may lead to deleterious self-fulfilling prophecies. For example, in the case of psychiatric diagnoses, treatable causes should be carefully sought before elderly patients are dismissed as senile. Once patients are treated as senile, it is all too easy for them to adapt by becoming senile. Even highly functional persons once admitted to psychiatric facilities have great difficulty getting out again.[17] With the elderly, the danger of iatrogenic effects is especially severe. The zone between therapeutic effectiveness and complications of therapy is treacherously narrow.

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